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AUTHOR Porterfield, Jan
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ABSTRACT

The Alaska Consortium for Transition Services (ACTS) is a federally funded project to develop and implement secondary transition planning for rural Alaska students with severe disabilities. Secondary transition is the process of change occurring as students prepare to move from high school to adult life. As rural Alaska's severely disabled children become adults and want to live more independently, program service options decrease. Especially for rural Alaskan students, effective planning would include curriculum that teaches skills relating to subsistence, communal, and cultural activities. Transition Planning (TP) helps disabled students join society as adults. ACTS works at the state, regional, and local level to establish a secondary TP model that is culturally sensitive and adaptable to the unique needs of each rural community. Effective TP should be early, individualized and systematic, and should include parent or caregiver participation. ACTS focuses on community-based service delivery and emphasizes cooperation among agencies. Each student's individual transition plan emphasizes community-based instruction and activities. Project work began in February 1988, and an ACTS Consortium was formed consisting of 66 people. Members of the Consortium work to encourage development of the secondary transition process throughout Alaska. Two schools in one rural district were chosen as project "development schools." The program was used to plan students' job training and recreation activities. The ACTS process will be revised and disseminated in other rural districts as the project progresses. (TES)

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Jan Porterfield, Ph.D.
Special Education Service Agency
2211-B Arca Drive
Anchorage, Alaska 99577

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ALASKA CONSORTIUM FOR TRANSITION SERVICES (ACTS)

Rural Transition Planning for Secondary Students with Severe Disabilities: The Alaska Experience

Secondary Transition for Students with Disabilities

Secondary transition is the process of change which occurs as a student prepares for and moves from high school to adult life. Planning for this transition is important for all students, but it is particularly important for students with severe disabilities, who typically need more assistance than their peers. Until recently, however, the transition of students with severe disabilities has not been given much attention. It was assumed that these students and their families would deal with it on their own, or perhaps get help from a social worker or other adult service provider.

Typically, there were few adult options for individuals with severe disabilities, and those that did exist, segregated individuals with disabilities from non-disabled individuals (for example, residential facilities, sheltered workshops, or activity centers). If options were few, actual placements in these services were even fewer, and individuals were often placed on waiting lists for several months (or even years) before a placement could be found. Individuals with severe disabilities often stayed in their parental homes with nothing constructive or fulfilling to do, and with few opportunities for social interactions apart from those with immediate family. Many families found that they could not cope with the intensity of this situation. Often relationships broke down and the person experiencing a disability was placed in a residential facility as an emergency measure.

Thankfully, services have improved, and attitudes and circumstances have changed. More small group and individual supported living accommodations are now available. New creative employment services and Supported Employment programs are now operating (if only on a small scale) in most parts of the country. More and more, individuals with disabilities are taking their rightful place alongside other citizens. More individuals with disabilities now live in ordinary houses in ordinary neighborhoods (rather than in institutions), have paid jobs in ordinary work places (rather than spending their days in 'sheltered workshops' or 'activity centers'), spend leisure and recreation time with people who have similar interests (instead of being placed with people with whom they have nothing in common, apart from being 'disabled'). These positive changes are due to the efforts of parents, service providers, and individuals with disabilities themselves who have shown the potential of persons with disabilities when they are given appropriate opportunities and supported in their efforts to achieve.

A major contribution to helping students with disabilities to take their rightful place in society as adults, is effective Individual Transition Planning (ITP). Starting transition planning as early as possible, certainly by the time the student enters high school, can have a significant impact on his/her success in making the transition to adult life. Individualized Education Plan (IEP) goals can be linked with the ITP so that the goals are practical and relevant to the

RC017259

student's future. While still in school, the student can begin to gain community living skills, establish leisure interests, and get work experience to determine the kind of employment or other day-time activity he/she prefers. If transition planning starts early enough and is done well, a student should be well established in his/her initial adult lifestyle (including living arrangements, employment or other adult day-time activity, recreational activities), and support mechanisms should be in place, before he/she actually leaves school.

Key elements of secondary transition planning

The following are common key elements of secondary transition planning models:

- The transition planning process should be individualized and systematic with specific outcomes in mind.
- It is essential to actively involve the individual as much as possible in all aspects of his/her transition planning.
- Parent/guardian/caregiver participation and early involvement in transition planning is important.
- Personnel from adult and community services (e.g., the Division of Vocational Rehabilitation) and organizations (e.g., Chamber of Commerce) should participate in transition planning.
- Transition planning should begin several years before the student leaves school.
- Transition planning should include living arrangements, social skills, leisure activities, as well as employment.
- Transition planning should use locally available alternatives.
- Adequate support services to maintain employment or subsistence activities and independent living as an adult must be arranged.

This paper describes the Alaska Consortium for Transition Services (ACTS), a three-year federally funded project being conducted by the Special Education Service Agency (SESA).

Purpose of the ACTS project

The purpose of the ACTS project is to develop and implement a process of secondary transition planning for students with severe disabilities living in rural and remote communities of Alaska.

The impetus for the project came from concern about the future of students with severe disabilities as they move into adult life. The project focuses on community-based service delivery and emphasizes collaboration between parents and/or caregivers, school districts, adult service agencies, and community organizations. The major difference between this project and other transition projects is its location - rural Alaska - and the unique features and characteristics of that location.

Background

Most of the Alaska is considered rural, and much of it remote, by standards applied in the lower forty-eight. Alaska has a huge land mass of 586,500 square miles (equal to the combined size of California, Texas, and Montana) and small, widely dispersed population of 525,000 (with nearly half of the population residing in the Anchorage area). Approximately 40% of all Alaskans live in communities of less than 1,000 people. Most of the people who live in rural Alaska are Native; and there are many different Native peoples, each with their own language and cultural values and norms.

In the recent past, students with disabilities in rural Alaska were removed from their homes and sent to one of the state's few urban centers or the lower forty-eight for evaluation, training, specialist care, and/or treatment. Most of these people were institutionalized, few returned to their home communities and some were never seen by their friends and relatives again.

It is now generally agreed that people with severe disabilities should receive services in their own communities, where they can maintain contact with their families and friends and participate in the ordinary community activities which enhance the quality of their lives. This is particularly important in Alaska where a move away from the person's home community may mean not only leaving familiar surroundings and close relationships, but the loss of the person's entire cultural heritage and experience.

Despite the desire to help people stay in their home communities, it has been difficult to provide services for students with disabilities in rural and remote communities. Often there is only one student in the village or small community who requires a particular special service, and it is not cost-effective to base a specialist in the community full time. Recently, Alaska and other rural states have made use of itinerant specialists who work with local teachers and other service providers to ensure that an individual receives appropriate services without leaving home.

There also are problems in the delivery of itinerant services because of geography, distance, climate, lack of a connecting road or rail system, and cultural and language differences among the people. Air transportation (consisting of jet services between major towns and charter service among most villages) is the only way for special service personnel to reach the villages. But flying has its problems. It is not at all uncommon to contend with last minute changes and delays due to weather. Thus factors such as severe weather conditions, almost non-existent road systems, and substantial distances between villages, offer a real challenge to the delivery of services to people with disabilities in remote areas of the state.

Even with these problems, few children (for example, those with serious medical conditions) must leave their home communities or school districts in order to receive the services they need. Currently, the educational needs of most children with handicaps are being met in their home communities. But what happens after high school?

As children with severe disabilities become adults the situation often changes. The person may want to live more independently, away from the parental home, or parents may want to see their relative settled in adult life or feel that they are no longer able to cope with the demands of living with a relative with a severe disability. Adult services are not mandated and the severe lack of day services means that most adults have no appropriate day-time activities. It is hard to imagine what the person will do when his/her days are not filled with attending school. In the recent past, many of these Alaskan 'school-leavers' were sent to Anchorage (or other larger cities). Apart from the problems this has caused for individuals and their families (discussed

above), this is no longer a real option because of long waiting lists for adult services in the larger cities.

Recently it has become a priority to find ways of helping students with disabilities who live in rural Alaska to make the transition to adult life while remaining in their own communities. Rural Alaska, however, has characteristics that make this transition especially challenging.

Many villages in rural Alaska have serious and wide-spread problems of drug and/or alcohol abuse, and in some, teenage suicide rates are high. It is difficult to confidently attribute the cause of these problems. It is clear, however, that the clash of the white and Native cultures is one contributing factor. This clash in values (for example, competition verses cooperation, independence verses inter-dependence) has been brought to rural Alaska in a number of ways. Those ways include the impact of television on the Native culture, the fact that the majority of teachers in rural Alaska are white while their students are almost entirely Native, etc.

In villages with these problems, it is very difficult for most high school students to make the transition to adult life. On the other hand, villages which are considered to be more 'traditional', do a good job of including and supporting all of their members; and this includes individuals with severe disabilities. In these villages, the transition is relatively easy, and individuals with disabilities move gradually into traditional adult roles alongside their peers.

Individual transition planning can be a tremendous help in enabling students with disabilities to remain in or near their home communities as adults. Through transition planning, the student, his/her family, and the local community can be prepared for the student's adult lifestyle; and the support systems and services required can be arranged. The content of transition models used in urban Alaska and the lower forty-eight, however, may not apply in rural and remote Alaska. In the majority of Alaskan villages there are few paid jobs and those that do exist are often held by village leaders. In many villages most people live by subsistence activities such as hunting, fishing, and gathering berries. Independence is not valued as much as inter-dependence. Community and cultural activities such as craft work and dance are highly valued. If transition planning is to have any relevance to 'bush' Alaska all of these activities and cultural norms must be taken into account and included as part of the student's transition plan. Effective transition planning should have a major impact on rural Alaska because the educational curriculum of students would include the skills they will need in adult life and, in rural Alaska, this will include subsistence, communal, and cultural activities.

Philosophy

The principle of normalization forms the underlying philosophy on which the activities of the ACTS project are based. Consistent with this philosophy is the belief that services should respond to individual needs within the cultural context. It is important in this project, therefore, to ensure that the transition goals which are set for individuals are consistent with the values of their culture and community.

When an Alaskan student with a severe handicap is preparing to leave school the adult activities that are important in and valued by the person's community (for example, paid employment, subsistence activities, crafts) need to be identified. The next task is to determine the options available, consider other options which might be created (for example, starting a small business), identify which of these the person would like to do, and how he/she can be prepared for (and/or supported in) the chosen option.

Components of the Alaska Transition Process

The ACTS project is developing a process for implementing secondary transition planning which is **culturally sensitive and adaptable** to the unique needs of each rural community and/or school district. The process includes:

1. cooperative agreements between school districts and adult service agencies (Interagency Agreements);

2. environmental assessments which will help to identify needs, adult options (including jobs, subsistence activities, residential accommodation, leisure activities), services, and resources available within the community;

3. identification of the strengths and needs of the individual and his/her family or primary caregivers;

4. Individual Transition Plans (ITP) for all secondary students with severe disabilities;

5. guidelines for meeting the student's post-school needs within his/her own community or community of choice;

6. materials and methods for training parents and personnel from school districts and adult service agencies in effective transition planning; and

7. materials and methods for increasing public awareness of the potential of individuals with severe disabilities to live in and contribute to their communities.

Each student's Individual Transition Plan (ITP) should emphasize community-based instruction and activities. The ITP should cover the areas of independent living; social, community, and leisure activities; and employment or subsistence activities. The student, his/her parents or guardians, teachers, and other current and future service providers (for example, teacher's assistant, education specialist, vocational rehabilitation counselor, residential service provider, employers) should be actively involved in the rural transition planning process. Where a needed service does not exist (for example, residential service) deficiencies are reported to the appropriate agency, and steps are taken at local, district, and state level to facilitate the development of the service.

Methods

The ACTS project is being conducted on three levels: 1) state, 2) district/region, and 3) local community.

At the state level, work is concentrated on facilitating the establishment of an Interagency Agreement between the Department of Education, Division of Vocational Rehabilitation and Division of Mental Health and Developmental Disabilities. The purpose of this agreement is to establish state guidelines for secondary transition planning and to develop cooperative funding mechanisms. These funding mechanisms would ensure that students with severe disabilities receive appropriate services as they prepare to leave school and the long-term support needed in adult life.

At district and local community levels the project focuses on the process involved in establishing a model of rural secondary transition. This process is made up of the steps involved in developing, establishing, and maintaining a system of transition planning. It is

expected that this process will be similar in most areas. The content and style of the transition planning system, however, are likely to vary from community to community depending on the needs and expectations of students with severe disabilities, their families and others in the community. For example, in each school district there will be a district-level interagency agreement between the school district and adult service providers. The steps necessary to establish the agreement will probably be similar in all districts. However, the content of the agreements is proving to be (and probably should be) very different, because of the different needs and resources of each community.

The collaborative process for rural secondary transition planning and implementation is being developed in two schools in one rural school district (the development site) during the 1988-89 school year.

During the 1989-90 school year, the revised process will be disseminated further in other school districts in Alaska through training, technical assistance, and support. Evaluative feedback will be used to further modify the procedures. Finally, the system will be disseminated to other rural states.

Examples

Following are examples of the kinds of activities that have formed part of transition plans for two students in different rural Alaska villages.

The first student is a 21 year old man in a village in the Lower Kuskokwim School District. This student experiences mental retardation. Prior to establishing his transition plan last year, this student spent his school day in a self-contained classroom. Outside of school he was known as a trouble maker, always hanging around and causing problems for people. Part of his transition plan was to find a job or other activity that he could do in the community to acquire job skills and help him gain self-confidence. His family and school staff worked together and were able to find him an unpaid job that would be of value to the community. The job they identified was vacuuming the village church. The vacuuming job was built into his school day, and his mother and the teaching aide taught him the skills needed to do a good job. He has learned to be on time, follow directions, and perform all of the tasks involved in the job efficiently. The people in the village now look at the young man positively, because they can see that he is capable of doing a job that is important to the village. The young man has developed feelings of positive self esteem, confidence, and self-worth by doing this activity. The skills he has learned can be built on and lead to learning other skills which also will contribute positively to village life. It would have been better if these activities had started when the student first entered high school so that he could have learned a variety of activities by the time he left school at 22. But even by starting at a later stage, the student has gained a great deal of skill and confidence, and his future looks much brighter than it did a year ago.

The second student is a fifteen year old girl who lives in a village in Yupiit School District. This student experiences multiple handicaps including vision problems and mental retardation. Prior to her transition plan this student spent her school day in a self-contained classroom and her time outside school was spent at home. Part of her transition plan was to begin learning work and leisure skills. She is learning work skills in the school kitchen and the leisure skill of weaving using a simple loom. The woven strips she makes can be used to trim for kuspuks (a dress worn by most Native women), guitar straps, belts, etc. She works at her weaving for two hours a day in school and earns money by selling the trim. In both her kitchen job and the weaving activity she is learning functional skills such as money management, vocabulary, ordering from catalogues, and socialization. These activities have helped her to feel better about herself and given her a purpose. The people in the village are very interested in her weaving because they now they can buy the trim they need in their own village, instead of ordering it

from catalogues, as they did previously. The other students in the school also admire this student, and are more accepting of her. She has started attending some classes with non-disabled students and now talks to students in these classes. Everyone in the village recognizes that she is much more capable than they previously thought. If she continues to do her kitchen job and weaving activity and learns some other work and leisure skills, by the time she leaves school she will be skilled at a variety of activities. She will probably always live at home or with a family member, but she will be a contributing member of her community.

Progress to date

Timeline

The project was funded from October 1987 to September 1990. Unfortunately, work did not begin until February 1988 because of difficulties in recruiting a project coordinator. The project Consortium has now been formed, the school district which serves as the development site selected, and piloting of the Individual Transition Planning (ITP) process is underway.

The Consortium

The Consortium is now comprised of 66 people from a wide range of disciplines representing most regions of the state. Active Consortium members include: representatives from twenty-two (22) of Alaska's fifty-five (55) School Districts, the Special Education Service Agency, the Division of Vocational Rehabilitation, the Division of Mental Health and Developmental Disabilities, the Department of Education, the Education Department at the University of Alaska Anchorage, the Governor's Council for the Handicapped and Gifted, the Association of the Village Council Presidents (Native organization), the Kodiak Native Association (Native organization), the Alaska Parent Coalition (a statewide parent group), Access Alaska (a non-profit organization which provides independent living services to people with physical disabilities), Challenge Alaska (a non-profit organization which provides recreational opportunities to people with physical disabilities), the Alaska Chamber of Commerce, and a parent from a remote village.

Members of the Consortium work together to encourage the development of the secondary transition process throughout Alaska. Consortium members participate by reviewing and evaluating the developments that are being implemented in the Lower Kuskokwim School District and by introducing developments in their own school districts, agencies, or communities. A very important aspect of Consortium members' role is networking: providing information, feedback, and support to each other.

The Consortium meets through both teleconference (a common but not entirely satisfactory mode in Alaska) and face-to-face meetings to discuss the focus of the project and its progress. At these meetings members, share information, help each other with problems, and discuss future developments.

The goals of the face-to-face meeting in September 1988 were:

- to give participants a common knowledge base and awareness of transition activities and post secondary options around the state
- to determine the individuals and activities which should be part of an effective transition planning process

- to develop action plans that could be used by each participant to help with the development of transition planning

- to establish mechanisms for communication, support, feedback, and problem solving among Consortium members and with others involved in the transition activities in Alaska.

Each participant took from the meeting an action plan and personal goals for developing transition planning. Following the meeting, ACTS staff contacted members who were not able to attend to encourage them to set goals. They regularly contact all Consortium members to follow-up on the action plans and goals by offering support and technical assistance.

The Development Site

The Lower Kuskokwim School District (LKSD) was selected by a sub-group of Consortium members. The decision was based on the following criteria for model site selection:

- Enthusiastic agreement to participate from:
  - Representatives of the School District
  - Director of Special Education
  - Principals of the schools to be involved in the project
  - Teachers working with students with severe handicaps in these schools
  - Students
  - Parents and/or other adult caregivers of students
  - Adult service providers (for example, Division of Vocational Rehabilitation, residential, supported employment)
  - Representatives of the Native Corporation

- A total of at least five students with severe handicaps between 16-22 years old attending the schools involved in the project.

- At least one student with a severe handicap making the transition from secondary school in 1989 and one or more in 1990.

- Students integrated into ordinary schools.

- Population of the district representative of rural Alaska.

- Reasonable access between participating schools

- Reasonable access from Anchorage (the base for project staff).

LKSD met all of the criteria and had additional characteristics (such as, a Vocational Rehabilitation counselor based in the regional center, the establishment of a new Community Services program and Supported Employment project) which enhanced the development of the transition process. Two schools, Bethel Regional High School (located in the regional center, population 7,000) and Kwethluk School (in a small village about 20 miles from Bethel, population 500) were selected by school district personnel as the development schools. ACTS project staff provide assistance and support as the process is developed, evaluated, and implemented in these schools.

ACTS staff visit Bethel and Kwethluk about once a month during the school year to assist in transition planning activities. They have been involved in a number activities including:

- meeting with members of the Bethel Transition Team (BTT) to draft, revise and finalize the cooperative interagency agreement which specifies the joint working arrangements which will help students make the transition from high school.

- assisting teachers with the selection and adaptation of recording forms and procedures for ITP meetings. (Examples of the forms will be provided at the presentation.)

- assisting teachers in piloting ITP meetings with students, parents, and adult service providers.

- participating in community meetings to inform members of the community about transition activities and find out about other resources that might help in the transition of students.

- presenting information on the ACTS project and the involvement with the school district to the Advisory School Board.

- planning of a video presentation in conjunction with the school district which will help to inform people in the rural communities of the need for secondary transition planning.

- visiting community adult facilities and resources to explore the possibilities for students who will be leaving high school in the next few years.

ITP Example

The first ITP meeting was held in Bethel for a 20 year old young woman who experiences mental retardation. As a regional center of 7,000 people Bethel has many more job opportunities and a wider range of services than smaller villages.

Attending the ITP meeting were the student's mother, the Special Education teacher, the DVR Counselor; the Job Coach from Bethel Community Services, and ACTS staff. The student did not attend the meeting although she was scheduled to do so. The student's mother and Special Education teacher decided not to involve the student in this first meeting. They felt uncertain about the process and did not want to cause the student any undue concern. Since the meeting the teacher and student's mother have discussed the meeting content with her.

At the meeting the goals for the student's ITP were prioritized, and activities for achieving the goals before she graduates from high school in May, 1990 were discussed. The main goals to be worked on are Job and Job Training, and Recreation and Leisure. This student has a supportive family who want to provide for her living arrangements, income, transportation, and medical care in the future. Some ideas were discussed to help specify ways in which the family might deal with each of these areas.

The ideas generated by the people attending the meeting were written on an ITP form. (This form was selected and modified by the teacher from several that had been collected from other transition projects in the lower forty-eight.) Another meeting was scheduled to determine the best way to meet the goals and to formalize the plan.

The ideas suggested for the prioritized goals were:

Job and Job Training - Job skills should continue to be worked on in school. The Job Coach suggested that, contingent on the approval of the student and her mother, a 20 hour/week supported employment placement be identified and initiated in the spring of 1989. Employment

would continue through the next school year so that her job skills would be in place when she left school.

The DVR Counselor suggested that the student be introduced to the program at Adult Basic Education so that her educational needs would continue to be met when she leaves high school.

Recreation and Leisure - It was agreed that the student should be introduced to the Skill Center (a day activity center for people with developmental disabilities and chronic mental illness) to help her develop social contacts and hobby interests. It was also suggested that she increase her participation in ordinary community activities, for example church, post office, shopping, and community events.

It was agreed that during the 1988-89 school year the student would gradually spend more and more time, up to four hours a day, in the community. This time would be divided among jobs arranged by the teacher (e.g., house cleaning with other students in her class), the Skill Center where she would develop leisure interests and social skills, Adult Basic Education where skills such a budgeting could be learned in an adult environment, and the Supported Employment placement. During the 1989-90 school year (her last year in school) the time she spends out of school would be increased until she is spending all of her time in the adult activities she will be involved in following graduation.

Dissemination Activities

Descriptions of the transition process and outcomes are being sent to other districts so that they can benefit from the experience of the development site. This will also enable other districts to assess the adaptability of the process to their own district. Only limited assistance can be provided to other districts wishing to implement the process due to financial and time constraints. However, feedback is being obtained from all districts and modifications will be made based on their collective experience.

In addition to the dissemination that can be done directly, project staff are working with the Education Specialists employed by the Special Education Service Agency (SESA), the agency which holds the project grant. These Education Specialists travel to most school districts in rural Alaska providing assistance to teachers who have students with low incidence disabilities in their classrooms. Many of the Education Specialists are working with secondary students and have been disseminating the ACTS transition process to these teachers.

Project staff are currently planning the first major dissemination activity to be held in Spring 1989. This will be a training event for teachers, DVR counselors, other adult service providers and parents. Teachers from the development site and others who have been piloting the process will share their experience with those who would like to introduce the transition planning process in their district. Positive examples, problems, and concerns will be gathered later from all those attending the workshop and incorporated into the final transition planning process manuals.

Conclusion

The purpose of the Alaska Consortium for Transition Services (ACTS) project is to develop ways of helping students with severe disabilities who live in rural Alaska to make successful transitions from high school to adult life. During the 1988-89 school year, work is concentrated on developing the transition planning process in one rural school district. The process will be revised and disseminated in other rural school districts in Alaska during the 1989-90 school year.

Individual transition planning usually begins several years before the student leaves school. Individual Transition Plans (ITPs) cover areas such as where the person might live; the job, subsistence activity or other valued adult activity he/she might do; and how he/she might spend leisure time. By linking the student's IEP to his/her transition plan, educational goals can be set which are practical, realistic, and relevant to the student's future. Becoming involved at an early stage helps adult service providers (such the Division of Vocational Rehabilitation and the Division of Mental Health and Developmental Disabilities) to better understand the abilities, needs, and preferences of the student and the concerns of his/her family. This involvement enables them to actively contribute to the planning process and helps to ensure that the services required by the student in adult life can be provided in his/her own community.

The success of the ACTS project relies on collaboration and joint planning at state, district, and local school levels. The Consortium encourages interagency agreements to facilitate the transition planning process at all three levels. The main focus of the project, however, is on developing a process which will help each student with a severe disability who lives in rural Alaska to make a successful transition into adult life.

The ACTS project encourages, facilitates, and supports the introduction of individual transition planning in rural Alaska. Much of the structure of the approach being used in Alaska is based on transition models which are used in other parts of the country. The difference is in the content of the transition plans and their application to rural Alaska. Many rural communities in Alaska have very few paid jobs and the majority of the people rely on subsistence activities, such as hunting, fishing, and gathering berries. The challenge for schools, therefore, is to adequately prepare students for their adult lives by including in the curriculum the skills they will need for these subsistence activities. Adult services too must adapt. Services such as residential support, job training schemes, and supported employment must be used creatively and flexibly, and be culturally sensitive, if they are to be relevant to Alaska's rural communities.